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Report of the Special Rapporteur on the rights of persons with disabilities

Note by the Secretariat

In her report, submitted to the Human Rights Council pursuant to Council resolution 26/20, the Special Rapporteur on the rights of persons with disabilities provides an overview of the activities undertaken since March 2015, as well as her thematic study on the right of persons with disabilities to participate in decision-making.

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I. Introduction

1. The present report is submitted by the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, to the Human Rights Council pursuant to its resolution 26/20. It describes the activities carried out by the Special Rapporteur since March 2015 and contains a thematic study on the right of persons with disabilities to participate in decision-making. In preparing the study, the Special Rapporteur analysed the responses to a questionnaire sent to Member States, national human rights institutions, agencies of the United Nations system, civil society organizations, and persons with disabilities and their representative organizations. As at 22 December 2015, she had received 144 responses.[1]

II. Activities of the Special Rapporteur

A. Country visits

2. In 2015, the Special Rapporteur conducted country visits to the Republic of Moldova from 10 to 17 September (see A/HRC/31/62/Add.1) and to Paraguay from 19 to 27 November (the report will be presented at the thirty-fourth session of the Council). She thanks the Governments of those States for their cooperation prior to and during the visits.

3. The Special Rapporteur has agreed to make country visits to Morocco and Zambia during the course of 2016 and has made requests to visit France and Indonesia.

B. Conferences, meetings and engagement with stakeholders

4. The Special Rapporteur participated in numerous conferences and expert meetings, which allowed her to exchange information, share good practices and raise awareness of disability-related issues. In March and April 2015, she participated in the Human Rights Council's annual interactive debate on the rights of persons with disabilities and in the day of general discussion on inclusive education organized by the Committee on the Rights of Persons with Disabilities. Throughout the year she engaged in the process leading to the 2016 World Humanitarian Summit, and she moderated a session on disability inclusion during the related global consultation that took place in Geneva.

5. In May 2015, the Special Rapporteur undertook an unofficial visit to Helsinki at the invitation of the Ministry for Foreign Affairs of Finland to discuss collaboration on her mandate with a broad range of actors working to promote and protect the rights of persons with disabilities. In the same month, she also participated in a high-level meeting on disability organized by the Latvian Presidency of the European Union.

6. In June 2015, the Special Rapporteur participated in the eighth annual Conference of States Parties to the Convention on the Rights of Persons with Disabilities in New York, and its parallel events. She was closely involved in the final stages of the process leading to the establishment of the Sustainable Development Goals. She advocated for the inclusion of stronger references to persons with disabilities in the 2030 Agenda for Sustainable Development, and for the adoption of indicators to measure progress in implementing the Sustainable Development Goals in relation to persons with disabilities.

[1] See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/DecisionMaking.aspx.

7. In September 2015, together with the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, she convened an expert meeting on persons deprived of their liberty because of their disability. The meeting provided an overview of existing forms of arbitrary detention on the basis of actual or perceived disability, while reaffirming the absolute prohibition of these practices. Experts acknowledged the need to find new alternatives to existing practices that would be respectful of the human dignity and integrity of persons with disabilities.

8. On 27 October 2015, she presented her annual report (A/70/297) to the General Assembly, on the right of persons with disabilities to social protection. In order to prepare the report she undertook extensive consultations on the subject, including by means of various expert meetings. The report was made available in accessible formats. In addition, she met with the Secretary-General to discuss how to better include persons with disabilities within the United Nations system. Also in October, she attended the annual meetings of the World Bank in Lima and participated in several related events.

9. To mark International Day of Persons with Disabilities, which was on 3 December 2015, the Special Rapporteur, together with other United Nations experts, United Nations agencies and disability advocacy organizations, organized several awareness-raising activities in Geneva.

10. Since her appointment, the Special Rapporteur has established contacts with other special procedure mandate holders and United Nations human rights mechanisms to coordinate action and to encourage them to include a disability perspective in their work. This collaboration has taken place with the Special Envoy of the Secretary-General on Disability and Accessibility, the United Nations Partnership to Promote the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities, the Committee on the Rights of the Child, the Special Rapporteur on the right to education, the Special Rapporteur on the right to health, the Special Rapporteur on the rights of indigenous peoples, the Special Rapporteur on the sale of children, child prostitution and child pornography, the Independent Expert on the enjoyment of all human rights by older persons, the Independent Expert on the enjoyment of human rights by persons with albinism, and the Working Group on the issue of discrimination against women in law and in practice.

11. She has also held consultations with other stakeholders, including the Victim Assistance Committee of the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on Their Destruction, the International Committee of the Red Cross, representatives of national human rights institutions, numerous persons with disabilities and their representative organizations, other non-governmental organizations (NGOs), academics and ambassadors.

C. Communications

12. Summaries of communications sent and replies received during the period covered by the present report are available in the communications reports of special procedures (see A/HRC/29/50 and A/HRC/30/27).

III. Participation of persons with disabilities in political and public life

A. Principle of participation

13. Participation is a core human rights principle, as well as a basic condition of democratic societies. Participation allows individuals to play a central role in their own development, as well as in the development of their communities. People have a right to participate in decisions that affect their lives, including those concerning their rights. The active and informed participation of different groups, including women, children, older persons, indigenous peoples and persons with disabilities, is not only consistent with but is also a requisite of a human rights-based approach.[2] It ensures active citizenship, good governance and social accountability.

14. Participation is firmly rooted in international law. It is established in the Universal Declaration of Human Rights that every person has the right to take part in the government of his or her country, directly or through chosen representatives, and the right to equal access to public service (art. 21). The principle of participation through the right to equal participation in public affairs, the right to vote and to be elected, and the right to have equal access to public service are reaffirmed in the International Covenant on Civil and Political Rights (art. 25). Participation has subsequently been codified as a principle and a human right in other international and regional human rights instruments, including the Convention on the Rights of Persons with Disabilities.[3]

15. The Convention on the Rights of Persons with Disabilities addresses participation as a cross-cutting issue. Participation is embodied in its preamble and in its purpose (art. 1), and it is recognized as a general principle (art. 3) and as a fundamental political right (art. 29). Participation is expressly mentioned in relation to the rights to independent living and being included in the community (art. 19), inclusive education (art. 24), habilitation and rehabilitation (art. 26) and participation in cultural life, recreation, leisure and sport (art. 30). The concept is also present in the article on children with disabilities (art. 7), and in the articles that prescribe prerequisites for enabling participation such as those on accessibility (art. 9) and on freedom of expression and opinion and access to information (art. 21). The Convention on the Rights of Persons with Disabilities further highlights the importance of participation in its articles on implementation and monitoring mechanisms (arts. 4, 33, 34 and 35) and on international cooperation (art. 32).

16. Effective and meaningful participation is at the core of the Convention on the Rights of Persons with Disabilities. This was demonstrated by the unprecedented involvement of civil society, particularly persons with disabilities and their representative organizations, in

[2] Office of the United Nations High Commissioner for Human Rights (OHCHR), *Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies*, para. 64.

[3] This right is also recognized in the International Covenant on Civil and Political Rights (art. 25), the International Convention on the Elimination of All Forms of Racial Discrimination (art. 5 (c)), the Convention on the Elimination of All Forms of Discrimination against Women (art. 7), the Convention on the Rights of the Child (arts. 12 and 23 (1)) and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (arts. 41 (1) and 42 (2)). Regional instruments include the Charter of Fundamental Rights of the European Union (arts. 39 and 40), Protocol No. 1 to the Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights) (art. 3), the African Charter on Human and Peoples' Rights (art. 13), the American Convention on Human Rights (art. 23) and the Inter-American Convention on Protecting the Human Rights of Older Persons (art. 27).

the processes of drafting and negotiating the Convention. Since the beginning of the debates, the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities was encouraged to adopt working methods that would allow full participation by relevant NGOs in its deliberations.[4] In what was a remarkable procedural innovation, the Ad Hoc Committee allowed representatives of NGOs to speak in all its public meetings,[5] and in its informal and closed meetings.[6] Furthermore, the Ad Hoc Committee included 12 representatives of NGOs, designated by representative organizations of persons with disabilities and their allies, in the Working Group in charge of drafting the text.[7] The General Assembly encouraged Member States to involve persons with disabilities and their representative organizations in the preparatory processes contributing to the work of the Ad Hoc Committee and to include persons with disabilities in their official delegations.[8] Importantly, NGOs were actively supported and funded so that they could participate in the negotiations.[9]

17. Such participatory processes had a positive impact on the quality of the treaty and its relevance for persons with disabilities. Furthermore, the importance given in the Convention on the Rights of Persons with Disabilities to full and effective participation by all persons with disabilities represents a profound paradigm shift in international human rights law whereby persons with disabilities are not "objects" to be cared for but rather "subjects" enjoying human rights and fundamental freedoms on an equal basis with others.[10] While the core international human rights instruments already considered persons with disabilities on an equal basis with others, before the adoption of the Convention on the Rights of Persons with Disabilities those legal obligations were rarely used to advance the rights of persons with disabilities.[11] Moreover, persons with disabilities faced significant barriers to participation in public life and often had their views disregarded in favour of those of representatives of "organizations for persons with disabilities" and other groups of "experts".

18. While participation in political and public life entails a web of specific rights, such as the rights to vote and be elected, to access public services, and to participate in the conduct of public affairs, other human rights and fundamental freedoms contribute significantly to public participation by persons with disabilities, such as the rights to freedom of expression, freedom of association and peaceful assembly. These rights enable persons with disabilities and their representative organizations to achieve change peacefully and legitimately through the democratic process.[12] The Convention on the Rights of Persons with Disabilities broadened the significance of the participation of persons with disabilities in decision-making to beyond the scope of political rights, ensuring that they could express their views in all matters affecting them.

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[4] See Commission on Human Rights resolution 2002/61.

[5] See www.un.org/esa/socdev/enable/rights/adhoca57357e.htm.

[6] See www.un.org/esa/socdev/enable/rights/ahc4reporte.htm.

[7] See www.un.org/esa/socdev/enable/rights/a_58_118_e.htm.

[8] General Assembly resolution 57/229, paras. 12 and 13.

[9] See A/AC.265/2004/3.

[10] Gerard Quinn, "Resisting the temptation of elegance", *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Oddný Mjöll Arnardóttir and Gerard Quinn, eds., p. 216.

[11] See Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations, 2002).

[12] Ibid., p. 21.

B. Right to vote and to be elected

19. Persons with disabilities must enjoy the right to vote and to be elected on an equal basis with others. No one should be restricted, either in law or in practice, in the enjoyment of political rights on the grounds of disability. States must guarantee the right of persons with disabilities to vote and to be elected, including by ensuring that the electoral process, the voting facilities and materials are adequate, accessible and easy to understand and use, and by facilitating the use of assistive and new technologies. States should also guarantee that voting by secret ballot can be carried out without intimidation, including through the assistance, at their request, of a person of their choice.

20. Worldwide, persons with disabilities face multiple forms of discrimination that prevent them from exercising their rights to vote and/or stand for election. Inaccessible voting processes hinder the participation of persons with disabilities in elections. The denial or restriction of legal capacity often triggers a denial of political rights to certain persons with disabilities, especially of the right to vote.[13] Similarly, being placed in a psychiatric or social institution often prevents persons with disabilities from exercising their right to vote.

C. Right to access public service

21. States must set objective and reasonable criteria for accessing public service positions, which do not directly or indirectly discriminate against persons with disabilities.[14] In line with the Convention on the Rights of Persons with Disabilities, States must take all necessary measures, including the provision of reasonable accommodation and support, to guarantee to persons with disabilities the right and the opportunity to hold office effectively and perform any public function at any level of government on an equal basis with others. States must also ensure that persons with disabilities are not excluded from public service positions because of inaccessible recruiting procedures, public buildings or services. Furthermore, States must take the specific measures necessary to accelerate or achieve de facto equality of persons with disabilities in accessing public service positions (art. 5), and enact policies and measures to ensure the employment of persons with disabilities in the public sector.

D. Right to participate in the conduct of public affairs

22. Persons with disabilities have the right to participate in the conduct of public affairs. This is a broad concept that includes all aspects of public administration and policymaking, and relates to the exercise of political power, including legislative, executive and administrative powers. It also covers participation in public debates and dialogues, as well as in peaceful demonstrations and meetings.[15]

23. Persons with disabilities may participate in the conduct of public affairs either directly or indirectly. Direct participation entails deciding on public issues through a referendum or other electoral process, as well as taking part in popular assemblies and in other consultative spaces established by the State to engage with its citizens.[16] Indirect

[13] Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) on equal recognition before the law, para. 48.

[14] Human Rights Committee, general comment No. 25 (1996) on participation in public affairs and the right to vote, para. 23.

[15] Ibid., paras. 8 and 25.

[16] Ibid., para. 6.

participation in public affairs can be exercised by voting freely to elect representatives, and through membership in civil society organizations (CSOs). CSOs comprise a wide range of non-State and voluntary organizations, associations, networks and groups formed by people within the social sphere of civil society, including representative organizations of persons with disabilities.[17] Therefore, participation must be ensured to both individuals and groups.[18]

24. States have an obligation under international human rights law to closely consult with and actively involve persons with disabilities in policymaking, through their representative organizations. Since the adoption in 1993 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the international community has consistently acknowledged that policymaking and programme implementation in relation to the rights of persons with disabilities is to be undertaken in close consultation with, and with the involvement of, representative organizations of persons with disabilities.[19] Accordingly, the Convention on the Rights of Persons with Disabilities clearly provides for the involvement and full participation of persons with disabilities and their representative organizations in monitoring its implementation, as well as in other decision-making processes, including legislative, administrative and other matters, that affect any of their rights.

IV. Participation of persons with disabilities in public decision-making

A. Importance of effective and meaningful participation

1. Participation for enhanced decisions: diverse perspectives for better outcomes

25. Diversity is a fundamental aspect of human existence. Human beings experience life from different perspectives in accordance with their multiple human traits or identities: sex, race, colour, ethnicity, sexual orientation, language, religion, origin, age, disability or any other status. This diversity is reflected in the way in which people take decisions, exercise agency and participate in society. Persons with disabilities are part of this human diversity and, arguably, embody one of the most heterogeneous population groups. Notwithstanding, despite decades of efforts, in practice persons with disabilities continue to face barriers to their participation as equal members of society, all over the world. They rarely occupy positions in governments, their opinions are seldom considered, and they are usually not consulted in policymaking, including on matters directly affecting them.

26. As was evident in the process leading to the adoption of the Convention on the Rights of Persons with Disabilities, the participation of persons with disabilities in public decision-making can have an enormous impact on government actions affecting them and can lead to better decisions, since persons with disabilities are best positioned to identify their own needs and the most suitable policies for meeting them. Their participation ensures that States' policies and programmes are devised on the basis of their needs and preferences. Therefore, the inclusion of persons with disabilities in public decision-making

[17] See www.who.int/civilsociety/documents/en/understanding_en.pdf.

[18] Committee on Economic, Social and Cultural Rights, general comment No. 16 (2005) on the equal right of men and women to the enjoyment of all economic, social and cultural rights, para. 37.

[19] Committee on Economic, Social and Cultural Rights, general comment No. 5 (1994) on persons with disabilities, para. 14.

will result in greater efficiency and a more equitable use of resources, leading to improved outcomes for persons with disabilities and their communities.

27. An inclusive society is one that values and celebrates diversity and recognizes that individuals with different experiences, talents and viewpoints bring new ideas and solutions. By bringing complementary and diverse perspectives, persons with disabilities can make a significant contribution to policymaking and decision-making, foster opportunities for innovation and efficiency, and better reflect the diverse demands of citizens. States that encourage the active participation of all their citizens, including persons with disabilities, are more likely to reduce tensions and thus increase social cohesion.[20]

2. Participation for agency and empowerment

28. Participation in itself can be a transformative tool for social change. Efforts to actively involve persons with disabilities in decision-making processes are important not only because they result in better decisions and more efficient outcomes, but also because they promote agency and empowerment. Through participation, citizens become more involved in public decisions and more informed about how policymaking works and how they can contribute to it. When persons with disabilities get involved in public decision-making, they develop advocacy and negotiation skills that enable them to better express their views and realize their aspirations. The more that persons with disabilities participate in such processes, the stronger their voices become. Indeed, an increase in social capital is strongly linked to an increase in participation.[21]

29. The effective and meaningful participation of persons with disabilities can also promote a sense of ownership.[22] Ownership among citizens should not be interpreted narrowly or underestimated, as it reinforces public acceptance and the successful implementation of public policy. Effective participation of persons with disabilities in all stages of policymaking will develop their sense of ownership and responsibility vis-à-vis public decisions and can reinforce the interest of administrations in decision-making driven by public preference.[23] Accordingly, such participation may contribute to enhanced public trust and reduced opposition to governments' decisions. Disability groups would also have the opportunity to develop a closer relationship with decision makers and policymakers and to influence the advocacy of other groups.

30. The participation of persons with disabilities can further enhance their sense of pride, as traditionally they have been either excluded from decision-making processes or included in a way that has not enabled their effective and meaningful engagement. The invisibility of persons with disabilities in public decision-making reinforces misperceptions towards them and, ultimately, contributes to a lack of awareness of their capabilities and rights as equal members of democratic societies. Their meaningful participation fosters respect and support for diversity in society, breaking down stereotypes and strengthening their identity as a group.

31. As persons with disabilities constitute at least 15 per cent of the global population, which equates to 1 billion people,[24] their participation in the implementation of policies and programmes can have a profound effect on societies. Their ability to actively participate in the labour market, education, family life, leisure, culture and sport on an equal basis with

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[20] See http://archivo.cepal.org/pdfs/2007/S0700669.pdf (in Spanish).

[21] See http://cprn3.library.carleton.ca/documents/12949_en.pdf.

[22] See www.msucommunitydevelopment.org/pubs/paul/Lachapelle%202008%20Ownership%20JCDS.pdf.

[23] See http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/imported/Journal_Issue1_Irving.pdf.

[24] World Health Organization, *World Report on Disability* (2011), p. 29.

others requires the breaking down of multiple cross-cutting attitudinal, structural and physical barriers. The inclusion of persons with disabilities in all matters, including but not limited to disability-specific processes, directly tackles these barriers and avoids the creation of new ones. Their active inclusion sends a clear message to decision makers and the society at large that persons with disabilities are rights holders capable of participating and engaging meaningfully at all levels of society.

3. Participation as a component of good governance

32. There is increasing recognition that participation is a critical component of good governance and democracy. Civil society is an important vehicle for channelling the interests and expectations of its members and groups who may be experiencing barriers in participation. CSOs are strategic actors that can encourage States' transparency and accountability and can encourage States to fight inequality and exclusion.[25] Organizations of persons with disabilities can play an important role in promoting effective governance, holding authorities accountable and making them responsive to their needs, and in improving public management and human rights protection. Responses to the questionnaire highlighted numerous good practices regarding the participation of persons with disabilities in public decision-making, which demonstrate their role and added value in policy design and in the subsequent implementation and monitoring processes.

33. State authorities would also benefit from regular engagement with persons with disabilities, to learn not only about their specific needs but also about the policies required to address them. This would also provide State officials with an opportunity to understand the valuable contribution that persons with disabilities can make in societies, and avoid perpetuating outdated approaches to disability that de facto exclude a particular segment of the population.

B. Ensuring the participation of representative organizations of persons with disabilities

1. Representative organizations of persons with disabilities

34. By stating that the primary obligation of States is to closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations, the Convention on the Rights of Persons with Disabilities addresses the fundamental challenge of a lack of direct participation of persons with disabilities. Following the motto of the disability movement, "nothing about us without us", persons with disabilities are recognized as the main interlocutors when it comes to the treaty's implementation and States should always give priority to their opinions in matters affecting them. Furthermore, in line with article 12 and the general principles of the Convention, the right to participate applies to all persons with disabilities, including those who might need extensive support in order to express their positions.

35. To ensure their participation, to mobilize social capital and to facilitate collective action among them, all persons with disabilities have the right to form, join and participate in CSOs, particularly representative organizations of persons with disabilities. International, national and local organizations of persons with disabilities strengthen the influence of the disability community, and play a mediating role between individuals and the State thus contributing to building inclusive societies where the rights of persons with disabilities are fully realized.

[25] See http://pdwa.escwa.org.lb/uploads/nv4584952.pdf.

36. Representative organizations of persons with disabilities are non-governmental membership-based organizations created with the aim of collectively acting, expressing, promoting, pursuing and/or defending a field of common interest. Led and controlled by persons with disabilities, these organizations should be recognized by the sector that they aim to represent, and may use different strategies to promote their goals, including advocacy, awareness-raising, service delivery and peer support. They can operate as individual organizations, coalitions, or umbrella organizations of persons with disabilities that seek to provide a coordinated voice of the disability movement in its interaction with public authorities. Organizations of parents of children with disabilities are key to facilitating, promoting and securing the autonomy and active participation of their children, with the will and preferences of the child always being respected and their evolving capacities always being taken into account.

37. The Convention on the Rights of Persons with Disabilities has accelerated the process of establishing organizations of self-advocates with intellectual disabilities, of autistic persons and of other individuals who may need extensive support to express their positions. Organizations of parents and relatives of persons requiring support have often played a role in providing such support and one can find organizations that include parents as well as self-advocates. The role of parents in such organizations should increasingly move towards the provision of support, with self-advocates in full control.

38. It is important to distinguish between organizations "of" persons with disabilities, which are led by persons with disabilities, and organizations "for" persons with disabilities, which are usually non-profit organizations that provide services to persons with disabilities and often also advocate on their behalf. This advocacy role needs to be carefully assessed, as it can easily happen that advocates seek to ensure the continuity of services, regardless of whether or not they are human rights-based or the preferred options of persons with disabilities. The failure of States to acknowledge the distinction between organizations "of" and "for" persons with disabilities lies at the heart of historical tensions between the two types of organization, such as those around legitimacy, choice and control, and the allocation of resources. In their pursuit of genuine participation by persons with disabilities in decision-making processes, States need to ensure that the will and preferences of persons with disabilities themselves are given priority.

2. Promoting the creation of organizations of persons with disabilities

39. States must create an enabling environment for the establishment and functioning of representative organizations of persons with disabilities as part of their obligations to uphold the right of freedom of association.[26] The Convention on the Rights of Persons with Disabilities requires that States promote the establishment of organizations of persons with disabilities to represent the latter at the international, national, regional and local levels (art. 29). Accordingly, States should adopt a policy framework that facilitates their establishment and sustained functioning,[27] which should include a review of the existing legislation, the provision of financial and other support, and the establishment of a formal

[26] See the International Covenant on Civil and Political Rights (art. 22), the International Covenant on Economic, Social and Cultural Rights (art. 8) and the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms.

[27] See www.icnl.org/programs/mena/afan/Docs/Models%20to%20Promote%20Cooperation%20English.pdf.

mechanism recognized by law ensuring that organizations of persons with disabilities can register as legal entities, participate and be consulted.[28]

40. Organizations of persons with disabilities often face major challenges in acquiring legal status, because registration procedures are inaccessible, expensive and bureaucratic. This constitutes an obstacle to obtaining legal personality and external funding and to qualifying for tax benefits. Moreover, regulations in many countries require that organizations of persons with disabilities belong to both a mainstream and a disability-specific register to acquire the necessary formal status. Consequently, numerous organizations representing persons with disabilities remain unregistered. States must implement registration systems that are simple, flexible, expeditious, fully accessible, non-onerous and/or even free of charge,[29] to facilitate the registration of organizations of persons with disabilities.

41. The promotion of an enabling environment for organizations of persons with disabilities to flourish remains a challenge in many countries. This demands not only a strategic response, but also a shared responsibility between a broader range of stakeholders that includes Governments, national human rights institutions, international cooperation agencies and the private sector.

3. Independence and autonomy

42. States have an obligation not to unduly obstruct the exercise of the right to freedom of association in law or in practice.[30] In that regard, representative organizations of persons with disabilities have the right to operate free from State interference in their affairs; their members should be free to determine their statutes, structure and activities and to make decisions without State intrusion.[31] States must therefore refrain from interfering in the decisions and activities of these organizations, and adopt all necessary measures, including legislative measures, to limit the ability of national, regional and local authorities to hinder their operations, such as by reviewing registration and funding requirements.

43. Globally, CSOs and human rights defenders are increasingly facing State restrictions on their operations.[32] In some countries, they are subject to reprisals by the State, in the form of restrictions, censorship, budget cuts, intimidation and baseless criminal charges. The Special Rapporteur has been informed of threats against organizations of persons with disabilities aimed at restricting their operations after they had advocated for their rights at the international level and denounced obstacles to registering and obtaining external funding. In such environments, persons with disabilities cannot fully exercise their right to public participation.

44. It is of concern that, in some countries, representative organizations of persons with disabilities that are truly independent lack a real space for operation and participation, whereas government-sponsored organizations can operate freely. States must refrain from requiring a legal entity to be established or an organization for persons with disabilities to be registered as a precondition to the exercise of freedom of association.[33]

45. States often justify and legitimize their interventions into an organization's functioning by claiming the need to enhance accountability and transparency, or to

[28] See CRPD/C/QAT/CO/1, para. 10.
[29] See A/70/266, para. 26.
[30] See A/HRC/20/27, para. 64.
[31] Ibid.
[32] See A/HRC/26/29 and A/70/217.
[33] See A/HRC/20/27, para. 56.

harmonize or coordinate their activities, when the real intention is, in most cases, to silence dissident opinions and turn such organizations into governmental appendages. However, representative organizations of persons with disabilities are not part of the public sector and cannot be subjected to regulation and control, unless it is prescribed by law and is necessary to protect a legitimate interest in a democratic society.[34] States must also ensure that members of representative organizations of persons with disabilities have unfettered access to an independent and impartial judicial body to resolve any internal disputes.

46. Finally, States must ensure that representative organizations of persons with disabilities can freely engage with national and international human rights monitoring mechanisms, including the Committee on the Rights of Persons with Disabilities, other treaty bodies, the universal periodic review, and the special procedures of the Human Rights Council.

4. Capacity-building

47. Capacity-building is another key component for the effective and meaningful participation of persons with disabilities. Advocacy is more likely to be successful when organizations work strategically, have a clear understanding of policy processes and invest in people skills. The empowerment of persons with disabilities involves the development of technical, administrative and communication skills, as well as the facilitation of access to information and tools concerning their rights, legislation and policymaking. Implementation of the many innovations in the Convention on the Rights of Persons with Disabilities requires a strong and independent disability movement, one that can adequately respond to the demands of participation on all matters relevant to the movement.

48. Structural challenges are a major obstacle to the participation of persons with disabilities in public decision-making. As education systems often fail to adequately include persons with disabilities, their opportunities and capacities to become successfully involved in public decision-making are limited. This also affects the institutional capacities of their representative organizations. The lack of social protection systems for securing sufficient income and employment opportunities also affects the capacity of persons with disabilities to devote time and effort to civil society.

49. Pursuant to their obligations under the Convention on the Rights of Persons with Disabilities, States should strengthen the capacity of representative organizations of persons with disabilities to participate in policymaking, by providing capacity-building and training on a rights-based approach to disability. States should also build the competencies, knowledge and skills required by representative organizations to advocate for their full and effective participation in society (e.g. on topics such as strategic planning, communication, information disclosure, stakeholder consultations, networking, advocacy and independent monitoring mechanisms).

50. While respecting the autonomy of such organizations, States should support them in developing stronger democratic governance principles (such as respect for human rights, the rule of law, transparency, accountability, pluralism and participation) and in strengthening their accountability, and should provide guidance on how to access funding and diversify their sources of support.

5. Funding

51. The ability of representative organizations of persons with disabilities to access funding and resources is an integral and vital part of the right to freedom of association and

[34] International Covenant on Civil and Political Rights, art. 22 (2).

the effective participation of persons with disabilities.[35] Funding stability is essential to ensure effective and sustainable work programmes, enabling organizations to grow internally. Any registered or unregistered organization should be able to seek and secure funds and resources from domestic and international donors, including private individuals, private companies, CSOs, States and international organizations.[36]

52. Securing sustainable funding is one of the main challenges faced by representative organizations of persons with disabilities. Contributions to the present report illustrate that some States have established temporary or permanent funds to support the functioning of these representative organizations as well as the participation of persons with disabilities in various decision-making processes. While those schemes are important for the sustainability of representative organizations, the broad discretion of State authorities to allocate resources is of concern, as it may affect the independence and autonomy of organizations. Moreover, it is worrisome that in some cases, State funds are only intended for the provision of services, which limits the funding opportunities for existing and potential organizations focusing primarily on advocacy.

53. When organizations are unable to access domestic funds to support their activities, due either to a lack of or the limited availability of government funding, or a lack of interest by the private sector, they often rely on external sources. In such cases, donors' preferences for funding activities rather than core institutional functions, as well as their sometimes narrow agendas, can prevent representative organizations of persons with disabilities from establishing a viable organizational structure. Such trends have an impact on organizations' long-term planning and engagement in a given area.[37] Furthermore, the lack of a financial or funding history prevents many grass-roots organizations from applying for any type of funding.

54. The recommendation formulated by the Committee on the Rights of Persons with Disabilities to increase the public resources available for representative organizations of persons with disabilities, including those representing children with disabilities, should be implemented to enable them to fulfil their role under the Convention on the Rights of Persons with Disabilities.[38] States should not only economically support the establishment and strengthening of organizations of persons with disabilities,[39] but also allow them to access foreign funding as a part of international cooperation, which CSOs are also entitled to benefit from.[40]

6. Strategic alliances

55. The building of networks, coalitions and strategic alliances is critical, as representative organizations of persons with disabilities cannot build inclusive societies in isolation. Networking and coalition-building are essential instruments for increasing collective influence, in terms of both organizational and advocacy capacity. They also facilitate exchanges of information, experiences and good practices, thereby enhancing chances for successful advocacy and contributing to pluralism and compromise.

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[35] See A/HRC/20/27, para. 68.

[36] Ibid.

[37] East African Community, Draft EAC civil society mobilization strategy (2010), p. 24.

[38] See CRPD/C/GAB/CO/1, para. 9; CRPD/C/KEN/CO/1, para. 8; CRPD/C/AUS/CO/1, para. 13; and CRPD/C/HUN/CO/1, para. 14.

[39] Standard Rules on the Equalization of Opportunities for Persons with Disabilities, rule 18.

[40] See A/59/401, para. 82.

56. Representative organizations of persons with disabilities should build collaborative relationships with other actors, including CSOs from other sectors, NGOs, human rights defenders, providers of services, political parties, multilateral organizations and international cooperation agencies, to work collectively for respect of the human rights and fundamental freedoms of persons with disabilities. Collaboration requires a common understanding of the human rights-based approach to disability, thus avoiding charity-based and paternalistic approaches. The rights of persons with disabilities are not "disability-specific" rights but universal human rights that apply to all human beings.

57. There are various types of cooperation that representative organizations of persons with disabilities engage in, such as promoting the mainstreaming of the rights of persons with disabilities in advocacy initiatives conducted by other groups subject to exclusion and discrimination, such as indigenous people or older persons. This approach is of particular importance since persons with disabilities have often been invisible and excluded from non-disability-specific discussions and processes.[41] Furthermore, representative organizations of persons with disabilities can benefit from the strengths and experience of other civil society movements to strengthen the disability movement.

7. Women and girls with disabilities

58. Because women and girls with disabilities have historically encountered many barriers to participation in public decision-making, due to power imbalances and multiple forms of discrimination, they have had fewer opportunities to establish or join organizations that can represent their needs as women and persons with disabilities. Consequently, despite the widespread human rights violations affecting them, the intersectionality between gender and disability-based issues is still not fully included in the work of the different stakeholders promoting the rights of persons with disabilities or the rights of women. Acknowledging this situation, the Convention on the Rights of Persons with Disabilities requires States to take all appropriate measures to ensure their full development, advancement and empowerment. States must take steps to eliminate the barriers that prevent their participation in public decision-making and must ensure that all participatory mechanisms and bodies take into account both disability- and gender-related factors and the complex interrelationships between them.

59. States should reach out directly to women and girls with disabilities, especially when cultural and social backgrounds make it unsafe for them to participate in open consultations. States must also establish adequate measures to guarantee that the perspectives of women and girls with disabilities are fully taken into account and that they will not suffer any reprisals for expressing their viewpoints and concerns, especially in relation to sexual and reproductive rights, gender-based violence and sexual violence.

8. Inclusiveness

60. States must promote the participation of persons with disabilities across all population groups, including those historically discriminated against or disadvantaged, such as indigenous people, poor or rural-based persons, lesbian, gay, bisexual, transgender and intersex persons, and others. States must also ensure that the voices of persons with disabilities from throughout the life cycle are heard (particularly those of children, adolescents and older persons) and from across the whole range of impairments and experiences of disability (including deaf persons, autistic persons, deafblind persons, and persons with psychosocial or intellectual disabilities).

[41] See A/HRC/28/58, para. 21 (d).

61. Representative organizations of persons with disabilities should promote the participation of women and girls with disabilities, as well as that of persons with disabilities from all population groups, as active members, in a spirit of pluralism and inclusiveness. While representative organizations of persons with disabilities may have different agendas and different engagement at various levels of government, this multiplicity of interests and strategies should not lead to the exclusion of specific groups of persons with disabilities. Only by embracing its diversity will the disability movement find its strength.

C. Promoting consultation and the active involvement of persons with disabilities

1. Legal framework

62. The Convention on the Rights of Persons with Disabilities requires States to adopt all appropriate legislative, administrative and other measures to ensure effective and active participation by persons with disabilities in public decision-making. This entails recognizing the right of persons with disabilities to both participation and association, as well as the right of organizations of persons with disabilities to represent persons with disabilities at the national, regional and local levels. States must also adopt a legal framework conducive to the direct and indirect participation of persons with disabilities in law and policymaking, amending or repealing legislation, regulations, customs and practices that limit the ability of persons with disabilities and their representative organizations to participate. The participation of persons with disabilities in public life must be a cross-cutting principle of good governance.

63. National legal frameworks must explicitly require that State authorities consult closely with and actively involve persons with disabilities (including women and children with disabilities) through their representative organizations, in the development and implementation of legislation and policies concerning issues relating to them. This requires prior consultations and engagement with representative organizations of persons with disabilities at all stages of public decision-making, including before the adoption of legislation, policies and programmes that affect them. This duty stretches beyond consultation and access to public decision-making spaces and moves into the areas of partnership, delegated power and citizen control.

64. Importantly, the phrase "concerning issues relating to persons with disabilities", as referred to in the Convention on the Rights of Persons with Disabilities, should be understood broadly, to cover a wide range of legislative, administrative and other measures that may directly or indirectly affect persons with disabilities. This includes any decision-making processes, whether disability-specific or mainstream, that might have an impact in their lives.

65. States must consult with and actively involve persons with disabilities in law and policymaking and establish formal mechanisms and remedies for challenging decisions adopted without this prerequisite of validity.

2. Institutionalized consultative bodies and mechanisms

66. Although the Convention on the Rights of Persons with Disabilities underscores the involvement of persons with disabilities in decision-making processes through their representative organizations, it does not provide guidance on how participation should be ensured. The Committee on the Rights of Persons with Disabilities has highlighted the need to establish formal mechanisms and protocols, at all levels of the government, to conduct systematic consultations with representative organizations of persons with disabilities.

These consultation mechanisms may include institutionalized consultative bodies and other formal mechanisms for direct participation.

67. Many countries have adopted national disability lead agencies and within those, coordinating committees or similar bodies composed of various government representatives, organizations of persons with disabilities and NGOs. States should strengthen these structures, so that they can serve as focal points or coordination mechanisms for the implementation of the Convention on the Rights of Persons with Disabilities and thus provide a permanent space for the participation of persons with disabilities.

68. While disability lead agencies can be effective for strengthening the relationship between the State and civil society, they should be complementary to direct consultations and dialogue through other formal mechanisms as their structure usually limits the number and diversity of representative organizations of persons with disabilities. Additional engagement mechanisms may take the form of round tables, participatory dialogues, public hearings or online consultations.

69. As certain groups of persons with disabilities face additional challenges to their participation in public life, they may be inadequately represented by existing representative organizations in a given country. Accordingly, States must not only encourage and support the participation of persons with disabilities from disadvantaged groups in representative organizations of persons with disabilities, but also show flexibility and establish consultative mechanisms to enable the participation of all persons with disabilities. This is particularly important for persons with multiple impairments, persons with intellectual or psychosocial disabilities, autistic persons and deafblind persons. States must devise outreach strategies aimed at ensuring the participation of these groups. The broad inclusion of persons with disabilities throughout the public decision-making process is one of the most effective tools for States to develop truly inclusive and diverse societies.

70. Finally, States must promote the participation of representative organizations of persons with disabilities beyond disability-specific consultative bodies and mechanisms. In many countries, although CSOs are part of different committees or collegiate bodies working on a variety of issues (such as poverty, employment or education), representative organizations of persons with disabilities are rarely invited to participate. As disability is a cross-cutting issue, representative organizations of persons with disabilities should have the same opportunity to participate in these forums as others do.

3. Non-discrimination

71. States must ensure the right to participate in decision-making for all persons with disabilities on an equal basis with others. They must therefore commit to guaranteeing this right without discrimination on the basis of disability, and to eliminating discrimination against persons with disabilities on the basis of their race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

72. As women and girls with disabilities are at a higher risk of facing multiple forms of discrimination, States must pay special attention to guaranteeing their right to participate actively and directly in all decision-making processes affecting their lives.

73. Whenever needed, States must also provide reasonable accommodation to persons with disabilities in all dialogue and consultation processes. This accommodation should include adequate time frames and the technical assistance necessary to ensure their

effective participation on an equal basis with others. Regrettably, many countries do not recognize this right or limit its scope to the employment sector.[42] However, according to international human rights law, States have an immediate duty to fulfil the right of reasonable accommodation, which is not subject to progressive realization and whose denial constitutes discrimination.[43]

74. In most countries, children with disabilities are not provided with disability and age-appropriate assistance to allow them to participate in decision-making processes that may be relevant in their lives. States should guarantee the right of children with disabilities to express their views freely on all matters affecting them and give their views due weight in accordance with their age and maturity, on an equal basis with other children.[44] Contributions to the present report illustrate the benefit of implementing disability-inclusive strategies and guidelines on children's participation in decision-making.

4. Accessibility

75. States must guarantee access to all facilities and procedures related to public decision-making and consultation. Accessibility is a precondition for persons with disabilities to fully participate in all aspects of life. Therefore, according to the Convention on the Rights of Persons with Disabilities, States must take appropriate measures to ensure that persons with disabilities have access, on an equal basis with others, to the physical environment, transportation, information and communications (including information technologies and systems) and other facilities and services open or provided to the public, in both urban and rural settings.

76. Without accessible information and communication, a range of persons with different disabilities cannot effectively participate in law-making and policymaking. This is particularly the case for persons with sensory and intellectual impairments. Generally, decision-making bodies and mechanisms neither produce nor disseminate information in accessible formats (such as easy-to-read), nor do they ensure the availability of sign language interpretation, guide interpreters for deafblind persons, or captioning during public debates. States must ensure that the entire public decision-making process is made accessible, including buildings, information, materials and communication pertaining to public debates.

77. New information and communications technologies, particularly the Internet, can significantly enhance the participation of persons with disabilities in public decision-making processes. There is a growing awareness of the role of the Internet in broadening the concept of "online citizenship", especially through e-government and e-democracy initiatives.[45] States should increase their efforts to reduce the access gap in the use of the Internet and other information and communications technologies, while ensuring full accessibility. Electronic participation should not prevent States from providing other forms of participation and consultation.

5. Good faith

78. States must consult and engage with representative organizations of persons with disabilities in good faith. This is a basic principle of good governance and international law, as stated in Article 2 (2) of the Charter of the United Nations. The principle of good faith

[42] See A/70/297, para. 71.
[43] Ibid.
[44] Convention on the Rights of Persons with Disabilities, art. 7 (3).
[45] See A/HRC/23/50, para. 31.

requires parties to deal honestly and fairly with each other, represent their motives and purposes truthfully, and refrain from taking any unfair advantage.[46]

79. Consequently, good faith should be a foundation stone of all State actions during processes of dialogue and consultation with representative organizations of persons with disabilities, and should permeate States' interpretations of their own rules for participation in public decisions. Consultations must embrace transparency, mutual respect, meaningful dialogue and a sincere desire to reach consensus. They must take place in accordance with procedures that are appropriate to the circumstances of the diversity of the disability movement and must allow for reasonable and realistic timelines.[47]

80. States should undertake periodic evaluations of the functioning of the different participation and consultation mechanisms, with the active involvement of representative organizations of persons with disabilities, to ensure that the principle of good faith is being respected. Contributions to the present report highlight the importance of developing codes of conduct for consultation and engagement with CSOs.

6. Awareness-raising

81. Due to stigma and segregation, persons with disabilities often remain invisible in society and their opinions are not duly taken into account or recognized as valid. States must raise the awareness of societies about the importance of persons with disabilities participating in public decisions and about the positive impact that they have on the decision-making. They should develop specific training programmes targeted at authorities and public officials, especially those involved in policymaking. These actions must be undertaken in consultation with representative organizations of persons with disabilities, and the active participation of persons with disabilities as teachers, instructors or advisors must be ensured.

82. States should implement awareness-raising training programmes on the rights of persons with disabilities. Organizations of persons with disabilities can contribute to these efforts by educating persons with disabilities about their rights and responsibilities and about how proposed policies and decisions would affect their lives. Awareness-raising and education programmes on a rights-based approach to disability can also contribute to the promotion and protection of democracy.

D. Key areas for participation

1. Legal harmonization

83. States parties to international and regional human rights instruments have an obligation to ensure that their domestic legislation is consistent with international standards. The Convention on the Rights of Persons with Disabilities requires States to adopt all the appropriate legislative measures to implement the human rights and fundamental freedoms of persons with disabilities, and to repeal any inconsistent legislation. Therefore, States should undertake a holistic review of the adequacy of their existing legislation, in view of their obligations under the Convention. During this process, States must closely consult with and actively involve persons with disabilities through their representative organizations.

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[46] Anthony D'Amato, "Good faith", *Encyclopedia of Public International Law* (1992), p. 599.

[47] See CRPD/C/HUN/CO/1, para. 14.

84. Persons with disabilities can participate in legislative processes in different ways. In many countries, citizens have the right to propose legislative initiatives, referendums and petitions, without the endorsement of political parties or State authorities. States must ensure that these direct democracy procedures are fully accessible for persons with disabilities.

85. While the legislative process may vary from country to country, legislatures should guarantee the participation of persons with disabilities throughout the entire process, including in deliberative assemblies or chambers that debate and vote on draft laws concerning issues relating to persons with disabilities. National legislatures should establish specific provisions in their rules of procedure to enable the participation of representative organizations of persons with disabilities in advisory groups and legislative committees, as well as in public hearings and online consultations. The accessibility of facilities and procedures must also be guaranteed.

2. Budgeting

86. The right of persons with disabilities to participate in public decision-making also covers public budgeting processes. Representative organizations of persons with disabilities can play an important role in public budgeting, by providing critical information on the concerns, needs and priorities of persons with disabilities. The participation of persons with disabilities and their representative organizations in public budgets ensures that resources are allocated to priority areas, and that bodies implementing mainstream and disability-specific policies and programmes are held accountable for their performance.

87. States are increasingly introducing participatory budgeting mechanisms, which enable citizens to influence the allocation of public resources through direct discussions and negotiations with authorities. Although participatory budget processes are a valuable opportunity for persons with disabilities to make States more responsive to their needs and preferences, their effectiveness depends upon the provision of accessibility and capacity-building.

88. Contributions to the present report have illustrated that persons with disabilities and their representative organizations are generally excluded from public budgeting processes. Inadequate resource allocation and inadequate identification of priority areas, including for funding participatory mechanisms and for representative organizations of persons with disabilities, are of concern. States must therefore adopt a framework that facilitates the participation of persons with disabilities and their representative organizations at all stages of the budgeting process.

3. National implementation and monitoring

89. Article 33 of the Convention on the Rights of Persons with Disabilities requires States to designate one or more government focal points and to consider the establishment of a coordination mechanism to advance and facilitate the implementation of the treaty at all levels. States are also required to establish an independent mechanism to monitor the implementation of the Convention. Involvement and full participation by persons with disabilities and their representative organizations is required not only in the monitoring process but in all the provisions within article 33.[48]

90. Consequently, the establishment of any national framework for the implementation or monitoring of the Convention on the Rights of Persons with Disabilities must include persons with disabilities through their organizations. These frameworks must be operated in

[48] See A/HRC/13/29, para. 70.

a transparent manner and persons with disabilities must be allowed to define the criteria of representativeness in accordance with their own procedures. The autonomy and independence of the monitoring mechanisms and of representative organizations must be ensured in order to enable their effectiveness.

4. International monitoring

91. The Convention on the Rights of Persons with Disabilities underscores the importance of the participation of persons with disabilities and their representative organizations at the international level. It invites States to consult and involve representative organizations of persons with disabilities in the preparation of State party reports to the Committee on the Rights of Persons with Disabilities (see art. 35 (4) of the Convention). States should also consult with persons with disabilities when preparing their reports for other human rights mechanisms, such as other treaty bodies, the universal periodic review and the special procedures.

92. The Convention on the Rights of Persons with Disabilities also invites States to closely consult and actively involve persons with disabilities, through their representative organizations, when nominating candidates to serve as experts for the Committee on the Rights of Persons with Disabilities (see art. 34 (3) of the Convention). This provides an opportunity for persons with disabilities to suggest qualified candidates and to be nominated as members of the Committee. States should encourage applications from persons with disabilities and support their participation in election processes for this Committee and those of other treaty bodies.

93. In recent years, several proposals have been made to strengthen the treaty body system and overcome past challenges, including engagement with civil society.[49] The ability of persons with disabilities and their representative organizations to participate in international human rights monitoring requires the availability of procedures and information in accessible formats. The universal periodic review, the human rights treaty bodies and the special procedures of the Human Rights Council, as well as regional human rights bodies, should increase efforts in this regard.

5. International decision-making processes

94. The requirement to involve persons with disabilities and their representative organizations extends to international decision-making processes. Such participation can ensure that the need and demands of persons with disabilities are adequately mainstreamed and integrated into the work of the United Nations system, including all its programmes, funds, specialized agencies and other bodies. The United Nations system should guarantee the participation of persons with disabilities through their representative organizations by proactively seeking their inputs in all international decision-making processes, including processes within the United Nations itself, such as the development and monitoring of system-wide action plans, strategic planning and management. For that purpose, the United Nations system should ensure the direct participation of persons with disabilities in international summits, high-level meetings, permanent forums and conferences of persons with disabilities. The participation of persons with disabilities and their representative organizations in all aspects of the implementation and monitoring process of the 2030 Agenda for Sustainable Development is imperative.

[49] OHCHR, "Strengthening the United Nations human rights treaty body system: a report by the United Nations High Commissioner for Human Rights" (2012); and Secretary-General of the United Nations, "Strengthening the United Nations: an agenda for further change" (2002).

95. International decision-making processes beyond the United Nations system are also crucial. The involvement and participation of representative organizations of persons with disabilities in the drafting of regional treaties, the adoption of international trade agreements, and the review and update of the World Bank safeguard policies, among other things, are equally important.

6. International cooperation

96. International cooperation is pivotal to support national efforts for the realization of the purpose and objectives of the Convention on the Rights of Persons with Disabilities, especially in developing countries. States must undertake appropriate and effective measures to foster international cooperation between and among States, including South-South and triangular cooperation, in partnership, as appropriate, with relevant international and regional organizations and CSOs, particularly organizations of persons with disabilities. Involvement and consultation by persons with disabilities is essential in order to ensure that they are both agents and beneficiaries of official development aid. States should take into account their expertise in identifying priority areas for funding, as well as key areas for capacity-building and research. Contributions to the present report illustrate the added value of establishing disability-inclusive consultative forums or working groups attached to national cooperation agencies.

97. The adoption of the Sustainable Development Goals with concrete references to persons with disabilities constitutes an excellent opportunity for achieving the coordinated engagement of international donors in the advancement of the rights of persons with disabilities. The Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development are complementary and should be mutually reinforced to guarantee the full inclusion and participation of persons with disabilities.

98. International cooperation agencies should directly engage with and support representative organizations of persons with disabilities, and should consider increasing funding to achieve that engagement and support. In recent years, many donors have reduced the number of regions and countries in which they operate, thereby affecting organizations of persons with disabilities in middle-income countries. Additionally, funding is often tied to the condition that organizations must provide a percentage of co-funding from another source, but many representative organizations of persons with disabilities are unable to comply with this requirement and are thus excluded from such aid. Donors should take this factor into account and show flexibility in their conditions.

V. Conclusions and recommendations

99. **The right of persons with disabilities to participate in political and public life on an equal basis with others encompasses the right to participate in decision-making. The latter is an essential condition for a human rights-based approach to development and the realization of the Sustainable Development Goals. The Convention on the Rights of Persons with Disabilities provides a robust framework for guaranteeing the participation of representative organizations of persons with disabilities, and their active involvement and participation in public decision-making. States must embrace these obligations as an opportunity to enhance good and effective governance and to foster agency and empowerment among persons with disabilities.**

100. **The Special Rapporteur offers the following recommendations to assist States in realizing the right of persons with disabilities to participate in decision-making:**

(a) Recognize in domestic legislation the right of persons with disabilities to participate in political and public life on an equal basis with others, including the right to participate in public decision-making;

(b) Create an enabling environment for the establishment and functioning of representative organizations of persons with disabilities, especially by:

(i) Adopting a policy framework favourable to their establishment and sustained operation;

(ii) Guaranteeing their independence and autonomy from the State;

(iii) Providing support for capacity-building;

(iv) Securing access to funding mechanisms, including public funding and international cooperation;

(c) Adopt legislation to require State authorities to closely consult with and actively involve persons with disabilities, including children and women with disabilities, through their representative organizations, in the development and implementation of legislation and policies that directly or indirectly concern them. States should establish formal mechanisms and remedies to challenge decisions that do not adhere to this requirement;

(d) Engage with women and girls with disabilities and secure their direct participation in all processes of public decision-making, and guarantee that such participation and consultation is conducted in a safe environment, particularly in processes relating to the development of legislative or policy measures regarding violence and sexual abuse;

(e) Ensure the participation of persons with disabilities and their representative organizations in all processes of legal harmonization with the Convention on the Rights of Persons with Disabilities, as well as in national implementation and monitoring;

(f) Actively involve and closely consult with persons with disabilities and their representative organizations in public budgeting processes and in international cooperation among States;

(g) Guarantee the accessibility of all facilities, procedures and information related to public decision-making and consultation;

(h) Provide reasonable accommodation to persons with disabilities in all procedures related to public decision-making and consultation;

(i) Adopt strategies to ensure the participation of persons with disabilities in decision-making and provide disability and age-appropriate assistance for their participation in such processes;

(j) Encourage and support the participation of persons with disabilities from disadvantaged groups, in particular those who experience discrimination on the basis of their race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status;

(k) Support the participation of persons with disabilities in international decision-making processes.

101. **The Special Rapporteur recommends that international cooperation agencies directly engage with and support representative organizations of persons with disabilities.**

102. **The Special Rapporteur recommends that the entire United Nations system continue its efforts to promote the participation of persons with disabilities in all international decision-making processes, especially in the implementation of the Sustainable Development Goals.**